SELF CARE IN LATER LIFE:

RESEARCH, PROGRAM, AND POLICY PERSPECTIVES

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Volume Overview: The Nature, Extent, and Modifiability of Self Care Behaviors in Later Life

Authors: Marcia Ory (National Institute on Aging), Gordon DeFriese (University of North Carolina) and Alfred Duncker (Administration on Aging)

The volume begins with an overview of conceptual and methodological issues in self-care research, practice and policy. Highlighting the importance of self-care for health promotion/disease prevention in later life, this introduction provides an historical context for viewing of self-care research, presents a working definition of self care and classification of its various types, briefly overview volume contents, and summarizes cross-cutting themes and emergent findings.

Chapter I: The Patterns of Self-Care Among Older Adults in Western Industrialized Societies

Author: Thomas Konrad (University of North Carolina)

The focus of this first paper is on epidemiological studies of health and illness among older adults, with special attention to the role of self-care in the maintenance of independent functioning among elderly populations. Available information is summarized indicating the extent to which self-care practices occur among different subgroups of older persons (e.g. gender and age-differences). This paper specifies the ways in which self- care practices are associated with various forms and degrees of morbidity, the risk of institutionalization and/or mortality.

Chapter II: The Dynamics and Process of Self-Care in Old Age

Author: Eleanor Stoller (University of Florida)

In this paper, the focus shifts to the current knowledge available to suggest the factors which tend to either encourage or discourage the practice of self-care skills by older adults. This paper gives attention to the contexts of self-care practice, including the role of social support networks in facilitating and encouraging these types of lay initiative in personal health, as well as the situational/environmental factors which make self- care practice more or less likely. It deals with the notions of symptom-response and the extent to which people differ with regard to the extent to which they define a given symptom or health deficit as requiring either self-care or other response. Gender, age and ethnicity differences are investigated.

Chapter III: The Research Basis for the Design and Implementation of Self-Care Programs

Author: Thomas Prohaska (University of Illinois)

Self care associated with the identification and diagnosis of health and illnesses conditions and care of chronic conditions have stressed symptom recognition skills, the ability to monitor changes in health status, and the development of self management skills. This paper discusses the research bases underlying programs designed to foster self-care activities and recommends priorities for self-care programs for older adults. Topics include issues such as participant recruitment and attrition, public health versus clinical approaches to self-care, as well as the importance of stages of care in self care activities. Examples of self-care programs designed to target specific self-care activities are examined in the context of research issues on self-care. Antecedents for successful development and maintenance of appropriate self-care practices are examined (e.g., the role of the family prior to and during the medical encounter and communication skills within health care settings).

Chapter IV: Evaluating Psychosocial Interventions for Promoting Self-Care Behaviors Among Older Adults

Author: William Rakowski (Brown University)

Psychosocial interventions for promoting health-enhancing behaviors and discouraging health-impairing ones represent one of the best opportunities for reducing preventable illness, injury, and disability in old age. This paper provides a comprehensive review of self care intervention research conducted to date, with special attention to the self-care behaviors that have been targeted for change, characteristics of the populations that have been studied, the types of interventions proposed, the effectiveness of different intervention strategies, and the gaps in existing research efforts. This synthesis of existing literature is critical for identifying the most promising strategies for promoting self-care behaviors. Specific recommendations about the feasibility of designing and testing psychosocial interventions to promote self-care behaviors in late life are highlighted.

Chapter V: Enhancing Self-Care Research: Exploring the Theoretical Underpinnings of Self Care

Authors: Elaine Leventhal, Howard Leventhal, and Chantal Robitaille (Rutgers University)

In order to move beyond descriptive self care research, it is critical to attend to the underlying social, behavioral and biological processes motivating health

beliefs and behaviors in later life. The paper by Leventhal, Leventhal and Robitaille discusses the advantages of theory based research over descriptive research. Comparing and contrasting several different theoretical approaches, this paper delineates the attributes of the self care process and illustrate how different theories address key parameters. The authors propose a dynamic self regulation model which not only views the individual as an active problem solver but also recognizes the influence of the socio-cultural context in determining older people's views of health and their health care actions. The linkage between theory and clinical application is addressed with attention to how practitioners can use knowledge about determinants of health beliefs and behaviors to shape older people's health promotion and treatment behaviors.

Chapter VI: The Role of Social Science Research in Understanding Technology Use among Older Adults.

Author: Laura Gitlin (Thomas Jefferson University)

Assistive technologies have become an important dimension of any assessment of the role of self-care in the total spectrum of health care services needed and used by persons with chronic and debilitating conditions. This paper reviews the extant literature on the use of assistive technology in self- care practice, providing a new perspective on the role of social science in the cumulative understanding of the role technology plays in extending the adaptability of human beings to the demands of their environments. The paper reviews the current theoretical models for understanding the role of technology in self-care, discusses the problems of measurement associated with the study of technology adaptation and use, and emphasizes the implications of this body of literature for health and social policy.

Cross-Cutting Papers on the Socio-Cultural Context of Self-Care Practices, Programs, and Policies

Although most self care research published in the United States has focused on middle-class, White Americans, it is important to understand similarities and differences in factors that predict self care behaviors and their consequences across diverse populations within the U.S. as well as in other Western industrialized societies. Toward this goal, we have included two cross-cutting papers on the socio-cultural context of self-care practices, programs, and policies.

Chapter VII: Self-care in Special Populations: What Do We Know about Self-care in Minority/Ethnic/Low-Income Populations?

Authors: Lucille Davis (Chicago State University) and May Wykle (Case Western Reserve University)

The first paper by Davis and Wykle examines cultural origins and beliefs about self care in minority and ethnic populations with specific reference to the experience of older Black Americans. Recognizing the dramatic diversity within the Black population, these authors lament the lack of studies that have examined minority differences taking socioeconomic and regional differences into account. Focused on low-income black elders, this paper provides a cultural context for understanding the importance of self care in promoting health among groups traditionally cutoff from majority social institutions. Much more research is needed to understand how self care practices differ between and among different ethnic/cultural groups.

Chapter VIII: International Perspectives on Self Care Research: What Can We Learn from Other Countries

Author: Kathryn Dean (Population Health Studies, Denmark)

The second cross-cutting paper by Dean provides an international perspective to enhance our understanding of factors influencing self care practice and research in the United States. This paper reveals how social systems interact with academic disciplines to influence attention given to different health care approaches and research priorities. Like the paper by Konrad, this paper also addresses the evolution of the self care concept and related disciplinary perspectives. However, unlike the U.S., in Europe and elsewhere, there appears to be a stronger connection between social policies, self care practice, and calls for a new research paradigm. Yet, we can all be benefit from emergent cross-cultural sharing of self care concepts, methodologies, and solutions that is leading to new political and research alliances. The recent cross-cultural merging of individual and social perspectives of self-care behaviors promises to bring greater benefits to both Americans and Europeans.

Afterword: Toward a Research Agenda for Addressing the Potential of Self-care in Later Life

Authors: Gordon DeFriese (University of North Carolina) , Marcia Ory (National Institute on Aging), and Donald Vickery (Self-Care Institute)

Synthesizing Conference papers and Work Group discussions, this volume ends with an integrative summary of research priorities and policy/practice implications of prominent issues related to self care in later life. DeFriese, Ory and Vickery conclude with a concrete set of recommendations for addressing the dearth of systematic studies on the nature, extent and modifiability of self-care behaviors across the life-course. Research on self care has moved past a nascent stage and the opportunity now exists to move the field forward by

adhering to some of the principles for future investment in self care research and aging identified in this final chapter.

Appendix I: Annotated Bibliography

Author: Alison Woomert (Battelle Research Institute)

An annotated bibliography of research findings and policy issues on self care and aging issues has been prepared by Alison Woomert, Ph.D. formerly of the Sheps Center for Health Services Research at the University of North Carolina at Chapel Hill. This bibliography includes information on the demographics of health and aging; the conceptualization of self-care vis-à-vis other types of health care; the patterns, nature and consequences of self care, and the design and evaluation of self care programs for older adults.

THE NATURE, EXTENT, AND MODIFIABILITY OF SELF-CARE BEHAVIORS IN LATER LIFE

Marcia G. Ory, Ph.D., M.P.H.
Gordon H. DeFriese, Ph.D.
Alfred P. Duncker, Ph.D.

A decade or so ago, the concept of self-care was a term used more often than not in a polemical way. Self-care was often advocated as a means to offset the perceived "medicalization" by professionals of common health and illness events (DeFriese, et al., 1989). Since that time, the term has evolved in usage to identify a participative role for laypersons in shaping both the processes and outcomes of the care they receive from professionals, a role extending to the self-management of chronic conditions. In recent years, American social scientists have turned their attention from self-care as a self-defensive reaction to a concern with understanding the nature, causes and consequences of a whole array of health behaviors--leading to a resurgence of interest in self care as a researchable area.

At the same time, health professionals and patient education activists, particularly those concerned with the management of specific chronic diseases, have incorporated self-care concepts and educational methods in their practices to better assist their patients (and their families). Self-care, in the space of a decade, has quietly been incorporated into the vocabulary and interventional approach of a variety of clinical disciplines with focal interests in assisting persons with specific forms of health and functional limitations. As managed care has come to play such an important role in the restructuring of American health care, so has self-care been given greater emphasis in the form of "demand management" strategies for increasing consumer self-reliance and decreasing the dependence on professionals for common health problems and concerns.

Much of the interest in self-care has focused on the maintenance of functional health and independence among persons with various forms of physical or cognitive limitations. Hence, the question of the potential value of self-care as a means of enhancing the long-term social and health independence of older adults is one of considerable national policy significance. Among the more prominent issues related to self-care are: 1) the patterns, dynamics and processes of self care behaviors practiced by older adults in Western industrialized societies; 2) the design, implementation, and evaluation of self-care programs; 3) the theoretical underpinnings explaining self-care processes and intervention approaches; 4) the role of technology in promoting self-care and successful aging; and 5) the socio-cultural context of self-care practices, programs and policies.

This volume represents an important step in the process of assessing the potential contribution which self-care may make to the field of aging and health. It brings together some of the nation's leading authorities on various aspects of self-care and the measurement of health status among older adults. The chapters of this volume are based, in part, on materials presented at the 1994 National Invitational Conference on Research Issues Related to Self-Care and Aging. Updated to reflect new information on self care and aging, the chapters presented here summarize the current state of knowledge regarding self-care among older adult populations; identify research, practice and policy gaps; and make recommendations regarding short- and long-term actions which may promote self-care practices among older adults. We see this volume as a valuable resource for researchers, practitioners, and policy makers interested in learning what older people can do for themselves to enhance their health and functioning.

Defining Self-Care

This volume incorporates a very general definition of self-care which is inclusive of a broad range of behaviors undertaken by individuals, often with the assistance and support of others, which have the intent and effect of maintaining or promoting health and functional independence. Also included are those actions persons take to detect and diagnose, prevent or treat common illnesses and conditions, either acute or chronic. We find the definition of self-care promulgated by a special work group convened by the World Health Organization (WHO, 1983) to be particularly relevant to the purposes and orientation of the volume:

> *Self-care in health refers to the activities individuals, families and communities undertake with the intention of enhancing health, preventing disease, limiting illness, and restoring health. These activities are derived from knowledge and skills from the pool of both professional and lay experience. They are undertaken by lay people on their own behalf, either separately or in participative collaboration with professionals.*

Following from this definition, we give emphasis to several key components of self-care behaviors, including the intent and purpose of a wide range of self-care practices, the knowledge base underlying health behavior and behavior change skills, and the relationship of self-care to other informal and formal types of care used by older people.

Organization of this Volume

The focus of chapter 1 by Konrad is on epidemiological studies of health and illness among older adults, with special attention to the role of self-care in the maintenance of independent functioning among elderly populations. Available information is summarized indicating the extent to which self-care practices occur among different subgroups of older persons and are associated with various forms and degrees of morbidity, the risk of institutionalization and/or mortality. New data from the National Survey of Self-Care and Aging are presented to document the patterns of self-care behaviors by age and gender.

In chapter 2 by Stoller, the focus shifts to the current knowledge available to suggest the factors which tend to either encourage or discourage the practice of self-care skills by older adults. This chapter gives attention to the contexts of self-care practice, including the role of social support networks in facilitating and encouraging these types of lay initiative in personal health, as well as the situational/environmental factors which make self-care practice more or less likely. Stoller deals with the notions of symptom-response and the extent to which people differ with regard to the extent to which they define a given symptom or health deficit as requiring either self-care or other response.

Self-care associated with the identification and diagnosis of acute health and illnesses conditions, and care of chronic conditions, have stressed symptom recognition skills, the ability to monitor changes in health status, and the development of self-management skills. In chapter 3, Prohaska discusses the research bases underlying programs designed to foster self-care activities and recommends priorities for self-care interventional/educational programs for older adults. Topics include issues such as participant recruitment, retention; public health versus clinical approaches to self-care; and the importance of stages of care in self-care activities. Examples of self-care programs designed to target specific self-care activities are examined in the context of research issues on self-care. Antecedents for successful development and maintenance of appropriate self-care practices are examined (e.g., the role of the family prior to and during the medical encounter and communication skills within health care settings).

Psychosocial interventions for promoting health-enhancing behaviors and discouraging health-impairing ones represent one of the best opportunities for reducing preventable illness, injury, and disability in old age. Chapter 4 by Rakowski provides a comprehensive review of self-care intervention research conducted to-date, with special attention to the self-care behaviors that have been targeted for change, characteristics of the populations that have been studied, the types of interventions proposed, the effectiveness of different intervention strategies, and the gaps in existing research efforts. Rakowski illustrates the various ways the measurement of self-care behavior itself may

"fit" with the attempt to understand the larger spectrum of health consequences and outcomes. This synthesis of existing literature is critical for identifying the most promising strategies for promoting self-care behaviors. Specific recommendations about the feasibility of designing and testing psychosocial interventions to promote self-care behaviors in late life are highlighted.

In order to move beyond descriptive self care research, it is critical to attend to the underlying social, behavioral and biological processes motivating health beliefs and behaviors in later life. In chapter 5, Leventhal, Leventhal and Robitaille discuss the advantages of theory based research over descriptive research. Comparing and contrasting several different theoretical approaches, this chapter delineates the attributes of the self care process and illustrate how different theories address key parameters. The authors propose a dynamic self regulation model which not only views the individual as an active problem solver but also recognizes the influence of the socio-cultural context in determining older people's views of health and their health care actions. The linkage between theory and clinical application is addressed with attention to how practitioners can use knowledge about determinants of health beliefs and behaviors to shape older people's health promotion and treatment behaviors.

Assistive technologies have become an important dimension of any assessment of the role of self-care in the total spectrum of health care services needed and used by persons with chronic and debilitating conditions. In chapter 6, Gitlin reviews the extant literature on the use of assistive technology in self-care practice, providing a new perspective on the role of social science in the cumulative understanding of the role technology plays in extending the adaptability of human beings to the demands of their environments. Gitlin also addresses the current theoretical models for understanding the role of technology in self-care, discusses the problems of measurement associated with the study of technology adaptation and use, and emphasizes the implications of this body of literature for health and social policy.

Although most self care research published in the United States has focused on middle-class, White Americans, it is important to understand similarities and differences in factors that predict self care behaviors and their consequences across diverse populations within the U.S. as well as in other Western industrialized societies. Toward this goal, we have included two cross-cutting chapters on the socio-cultural context of self-care practices, programs, and policies. In Chapter 7, Davis and Wykle examine cultural origins and beliefs about self care in minority and ethnic populations with specific reference to the experience of older Black Americans. Recognizing the dramatic diversity within the Black population, these authors lament the lack of studies that have examined minority differences taking socioeconomic and regional differences into account. Focusing on low-income black elders, this chapter provides a

cultural context for understanding the importance of self care in promoting health among groups traditionally cutoff from majority social institutions. Much more research is needed to understand how self care practices differ between and among different ethnic/cultural groups.

Chapter 8 by Dean provides an international perspective to enhance our understanding of factors influencing self care practice and research in the United States. This chapter reveals how social systems interact with academic disciplines to influence attention given to different health care approaches and research priorities. As in chapter 1 by Konrad, this chapter also addresses the evolution of the self care concept and related disciplinary perspectives. However, unlike the U.S., in Europe and elsewhere, there appears to be a stronger connection between social policies and self care practice. Underscoring the advantages of a cross-cultural sharing of self care concepts, methodologies, and solutions, Dean calls for a new research paradigm addressing the place of self-care in health care in different countries. A more integrative perspective of self-care practice and policy that combines both individual and social approaches promises to bring greater health benefits for all.

This volume's Afterword provides an integrative summary of research priorities and policy/practice implications of prominent issues related to self care in later life. As editors of this volume, we are joined by our colleague Donald M. Vickery in offering a synthesis of the volume's content. We conclude with recommendations for addressing the dearth of systematic studies on the nature, extent and modifiability of self-care behaviors across the life-course. Research on self care has moved past a nascent stage and the opportunity now exists to move the field forward by adhering to some of the principles for future investment in self care research and aging identified in this Afterword.

Emergent Self-Care Themes

The Nature, Extent and Process of Self-Care Practices

As indicated in the chapters to follow, one of the major advances in self-care research over the past few years has been the specification of different types of self-care behaviors. Inconsistent research findings can be attributed, in part, to a failure to specify the antecedents and consequences of specific self-care behaviors. Three general categories of self-care practices are of importance in understanding the relationships among self-care practices and health outcomes: (a) steps taken by lay persons to compensate or adjust for functional limitations affecting routine activities of daily living; (b) actions taken to either prevent disease or promote general health status through health promotion or other lifestyle modification efforts; and (c) medical self-care for the diagnosis or treatment of minor symptoms of ill health or the self-

management of chronic health conditions. With regard to the first of these types of self-care, it is now clear that older adults who have experienced one or more significant declinations in functional capacity may offset these limitations through the use of assistive devices, the modifications of one's living environment, or through one of several types of activity modifications. The point of these self-care practices is to restructure the physical or social environment of the individual so as to retard the progression of a "functional limitation" which, if unattended, may become a "disability." Findings reported from the first wave of the NIA-supported National Survey of Self-Care and Aging indicate that there is no direct relationship of age to the extent of self-care practice. Rather, the tendency to engage in these practices is mediated by the presence of physical impairments, the social circumstances in which one lives, and the availability of social support.

With regard to general health promotive behaviors among older adults, it appears that there are significant secular changes taking place within the older age groups, some with negative impact while others have a more positive implication for older adults. As an example, on the one hand, there are indications of increased interest among hypertensive men, for example, in the monitoring of blood pressure and adherence to medication regimen. On the other hand, there are disturbing signs of an increase in the number of older women smokers and reduced rates of smoking cessation among this group. These kinds of secular trends are suggestive of the many aspects of lifestyle change and health promotive self-care practices which may have to be taken into account in the design and implementation of programs targeting health issues pertinent to these older adult populations in the years ahead.

With regard to medical self-care, there is considerable evidence that many older adults tend to "normalize" illness symptoms and health complaints and to attribute them to the fact of aging itself. Many of the reactions of older adults to the symptoms of ill health are grounded in cultural and ethnic traditions. However, few studies have examined cultural differences in self-care behaviors systematically, taking into account the interacting influences of socio-economic status differentials, or examine within-group cultural differences. There is even less appreciation of international differences which set the context for self-care practices.

Self-care, informal care, and formal care are often traditionally viewed as three distinct types of self-care, with substitution among care providers as a major policy issue for those concerned about escalating health care costs. Recent studies suggest, however, that these are arbitrary demarcations and that there is an interplay of different types of care over the illness episode of care among various subpopulations.

Among the factors accounting for the variability among individual older adults in reaction to illness symptoms are characteristics of the symptoms themselves (e.g., severity, pain, acuity, pattern of experience -- intermittent, non-specific, mild/slow onset), and situational factors, such as the social roles played by the individual and the settings within which the individual lives and experiences these symptoms. We also know that older women tend to react differently to illness symptoms than do men. Among both men and women, patterns of lay consultation with peers, as well as significant persons in one's primary group (such as adult children), can have significant influence on the way in which a symptom is perceived and the likelihood of eventual activity in response to a given symptom.

Much of the most illuminating research in this field has contributed in recent years to an emerging general model of health behavior which acknowledges the dynamic nature and situation-specific qualities of meanings associated with illness, its symptoms and various types of functional limitations. Our understandings of the behavior of older adults (and those in their primary relationships) in the face of illness symptoms or functional decrements seems to require an increased emphasis on both the *epidemiology* of these conditions among these older adult populations, as well as a deeper and more intensive understanding of the *process* through which individuals attempt to *regulate* the quality of their environments and make behavioral and environmental adjustments to the shifting health conditions they face day-by-day. Among the most important considerations of theoretical and practical importance to research in these areas are such factors as self-assessed health status (which seems to be a powerful predictor of the seriousness with which symptoms are treated via self-care), the body awareness of the individual (which is a psychological phenomenon more prominent among older males than among older women, although women tend to use more formal health care services than men), and the extent of confidence older persons have in the efficacy of formal medical care and physicians in particular.

Though we have known for several decades about the variability among social groups in patterns of response to illness symptoms, we are now much more aware of the intra-individual variability in response to symptoms (both over time and across different life situations) associated with these important factors. Yet, we can not ignore social structural influences on self-care practices, and are now being urged to turn our attention to family and community-level influences, as well as "upstream" approaches and supports for self-care behaviors.

There seems to be an increasing societal level of skepticism about the capabilities and effectiveness of medical therapies by physicians that has permeated even the older adult population. When combined with worries about the cost and experiences of lower quality and otherwise unacceptable

processes of formal care, these factors have tended to make self-care for common acute illnesses and the day-to-day self-management of chronic conditions, a much more prevalent response than perhaps would have been the case a decade or so ago.

The Design and Evaluation of Interventions to Encourage Self-Care Practice Among Older Adults

There is now a growing research basis for the design and evaluation of self-care programs. As indicated in the chapters to follow, there is an emergence of carefully-designed studies testing the effectiveness of diverse interventions based on theoretical models of health behavior and behavioral change (e.g., cognitive rational decision-based models). There is now an awareness of the importance of considering the stages of behavioral change and the need to tailor interventions according to specific stages (e.g., whether individuals are in the precontemplation, contemplation, preparation, action or maintenance stage). Several common components of self-care programs can be identified, including: (1) the provision of information to impart knowledge relevant to the practice of self-care skills; (2) methods to motivate the older individual to adopt relevant and appropriate self-care behaviors; (3) meaningful and timely feedback on the consequences of self-care practices; and (4) attention to environmental factors that continue to support the desired patterns of self-care practices and behaviors.

An extensive variety of formal courses and curricula have offered opportunities for older adults to acquire specific types of self-care skills. Many of these interventions have been studied rigorously and reported in the formal literature, and a substantial number have involved randomized assignment among intervention and control groups. The lessons from this body of experience and literature can inform future efforts to design and evaluate interventions for each of the three broad categories of self-care.

One of the issues apparent from a review of extant literature on the subject concerns the situations under which it is appropriate to focus on a self-care practice (or set of practices) as the primary dependent measure of intervention effect. Though the question of the most appropriate fit of self-care in this chain of effect may pose difficult theoretical and design questions, there are clearly situations where self-care can and does adequately serve as the appropriate outcome. Smoking cessation self-care education interventions serve as one example, where the self-care practice has been previously established to be related to longer-term health consequences and no longer requires the additional effort to establish the epidemiological relationship with other health outcomes. In these situations, it is sufficient to demonstrate the intervention's impact in terms of the targeted health behavior (e.g., smoking cessation) as an outcome.

Though self-care educational interventions for older adults, like most health promotion programs for other adult age groups, have encountered problems in both the recruitment and retention of participants, evidence from carefully evaluated interventions to address lifestyle and health promotion goals indicates that these programs have demonstrable positive effects among those who participate most actively, as measured by changes in key outcome variables. Nevertheless, results are mixed, and reasons for differences have been difficult to isolate because of the diversity of interventions and studies in this body of literature. This suggests that the *dose-response* relationship between self-care interventions and their presumed and targeted outcomes deserves further investigation. Further research can elucidate the extent to which recruitment and retention of older adult participants can be enhanced by including family and friends in these courses who are likely to offer social support with the learning and practice of these self-care skills.

There is a growing recognition of the importance of translating the benefits of self-care education and practice into a form which can be more widely disseminated through population-based and public health-oriented programs designed to improve the health of large groups of older adults. Some means of varying the messages and the mode of transmission to accommodate the highly variable target audiences for these interventions seems needed. There is considerable concern over the absence in this body of literature and experience of a genuine public health application of self-care concepts and approaches in meeting the health needs of older adults from diverse backgrounds.

A great deal of the emphasis in the intervention literature seems to focus on the technological aspects of self-care instruction and eventual practice. Many of the most widely cited self-care studies are multi-component intervention approaches, which lack the capacity to desegregate the separate effects of individual program components on knowledge gained, skills demonstrated, survival, functional health status, health care utilization or cost. We recommend that there be some future effort to conceptualize studies of self-care educational approaches to broad public health aspects of aging, with the emphasis on scope and reach, as well as on health outcomes or the use of assistive technologies. Moreover, there is room in such studies for participation of researchers from different disciplines who may have quite different interests in self-care; some may focus on the setting within which self-care skills are learned or practiced; others may focus on the intervention methods themselves; and a third group may focus on the response of specific target groups to these interventions.

Conclusion

Over the past 25 years, self-care behaviors have been associated with a multitude of health outcomes. Recent research studies has expanded the knowledge base by specifying different types of self-care behaviors, identifying factors influencing the development and maintenance of different types of self-care behaviors in different populations, and evaluating the effectiveness of social and behavioral interventions for modifying self-care practices throughout the life-course. This complexity of research presents a formidable challenge, but, unlike the early years of self-care research, there is now a concerted multi-disciplinary research effort, combining the best conceptualizations and methodologies from both the social and clinical sciences.

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TOWARD A RESEARCH AGENDA FOR ADDRESSING THE POTENTIAL OF SELF-CARE IN LATER LIFE

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Research Needs and Priorities in Relation to Self-Care and Aging

While there has been a resurgence of self-care research in the past decade, there is still a dearth of systematic studies on the nature, extent and modifiability of self-care behaviors across the lifecourse. We need to know much more about the readiness for and acceptance of self-care and health promotion behaviors among older adult populations, a concern which must include a consideration of the variability among special populations (e.g., minorities, low-income populations) in response to these ideas and practices. In this connection, we need to know more about the way in which notions of prospective health are incorporated within the life-course and world-view of the older adult.

Additional information is needed about the way in which patterns of self-care cluster with other aspects of health behavior and attitudes. Are those who practice medical self-care for minor illnesses or health conditions also likely to cope with functional limitations through self-care, or use positive behavioral approaches to health promotion and enhancement? Are some types of self-care practices essentially redundant (or do they duplicate the effects of other types of self-care behavior)?

We need to know more about the extent to which the individual lay person's decision to engage in self-care for a given symptom or condition is automatic and reactive, or whether there is an elaborate decision-making process through which information is sifted and sorted while actions are planned accordingly. If we are to consider the way in which self-care by lay persons interrelates with formal (often primary) care from physicians, nurses, or other health care professionals, then there is a need to develop strategies for involving health care providers in the process of designing educational programs to impart these skills and this knowledge to lay persons.

In view of the variability in self-care practice among older adult populations, we need to devote significantly more research attention to understanding the availability of opportunities for self-care and other less professionally-

dependent responses to symptoms than we know at the moment. This would include increased information about the levels of self-care knowledge and capabilities among older adults of differing social situations.

In this same direction, there is a need for increased knowledge about the appropriateness of lay self-care response to illness symptoms or functional limitations, as well as knowledge of the extent to which self-care skills and information need periodic renewal, as in the sense of continuing education. In this connection, there is an important need for better clarity about the most relevant outcomes of each of the three domains of self-care (e.g., health promotion/disease prevention, chronic disease/assistive care, and medical self-care).

We also know that, over a lifetime, self-care may be practiced for quite different reasons at different periods in one's life (early, in response to acute illness conditions; later in response to more chronic conditions). We need better understanding of the so-called trajectories of self-care as a basis for better targeting the interventions for different age cohorts. Here again, the impact of social and cultural factors may prove to be important mediating influences on the effect of self-care.

One of the most important issues reiterated throughout this volume is the need for encouraging diversity in intervention research. This includes research on self-care among older adults which addresses the variation in self-care which may occur among:

settings (e.g., health care programs and facilities, senior centers, retirement communities);
geographic areas (e.g., rural, small town, urban areas);
population subgroups (e.g., African Americans, Hispanics, Asian Americans); and
delivery mechanisms (e.g., different types of health care organizations and providers).

Too few self-care studies have been conducted among underserved populations. It is very important that such research take place through effective and genuine community/practitioner and researcher partnerships, that such expectation for these partnerships be built into research solicitations. It is important to discover whether interventions "proven" to work in certain contexts also are effective with underserved populations.

The Readiness of the Self-Care Arena for Addressing These Important Research Issues

The chapters contained in this volume address the readiness of the research community to address key aging and self-care issues. It is time to move toward

a more systematic and integrated program of study, rather than relying on post-hoc analyses. Several observations can be made which together suggest the present capacity and commitment to carry out the kinds of studies thought necessary in this area. First of all, intervention research is iterative science. In intervention research, one of the principal objectives is to constantly extend the boundaries of current knowledge and experience with respect to particular interventions among different target groups. It is important to discover whether what works for middle class white older adults also works for African-American older adults. This is a developmental process that moves in at least two directions. Building process and cost analyses into a study can provide not only information about whether or not an intervention worked, but can provide insight into why it did or did not work, and can identify useful parameters (for example, the cost of a successful smoking cessation program among older adults).

There are now many previously unrecognized opportunities to "piggyback" investigations of self-care on existing studies and existing databases to answer questions about interventions (e.g., the cost-effectiveness of interventions or the impact of interventions on health outcomes). Piggybacking is more than secondary data analysis and reviewing existing information. It emphasizes collaboration, for example, where one researcher may be an interventionist and another may be a process evaluator. Collaborating on existing studies may provide added insights. Piggyback collaboration also may provide an efficient mechanism for collecting sets of items of interest to different researchers or developing larger databases with multiple uses.

Given the importance of process to implementation success for self-care interventions, researchers should be encouraged to document and study the process and implementation of intervention research in this field in order to find out not only what works, but what did not work, for whom does it work or not, and under what conditions. Not only is process evaluation helpful to the next study, but process analysis also is important to practice and informs practitioners about how to implement the basic intervention under conditions of practice.

Research is now underway, involving investigators with requisite expertise, addressing each of the three domains of self-care -- health promotion/disease prevention, chronic disease/assistive care, and medical self-care. Knowledge and implementation experience in each of these domains are at quite different stages in terms of scientific development, and different theoretical models may apply to each. Yet, research in all three is important and needs attention.

The need at present is for a progression of research at several levels -- from developmental and theory-based research, to pilot and observational studies, to more controlled studies and randomized control trials (RCTs). We need to be

able to conduct subgroup and cost analyses related to a wide variety of interventions conducted in a diverse range of settings. We need efficacy studies, and then effectiveness and cost-effectiveness studies. This sequence of research not only advances science, but also helps to assure that resources are not ineffectively allocated to RCTs before there is a solid foundation of research at an earlier phase.

Principles for Future Investment in Self-Care and Aging Research

The following principles are offered as guides to further investment in this area:

- Research on self-care and aging should carefully differentiate self-care practices in each of the three principal domains (health promotion/disease prevention, chronic disease/assistive care, and medical self-care).
- Research on self-care and aging should specify the structural context within which proposed interventions will be launched and look for opportunities to study the differential effectiveness of these interventions across a number of venues.
- Research in this area should carefully define the various subcomponents of interventions and make special effort to measure and assess the relative contributions of each to the overall impact of these interventions wherever possible.
- Within this field there is a need for a common and standardized core measures of key variables (symptoms, symptom response, health outcomes, quality of life, etc.) and there should be some insistence that future research in this field contributes to the cumulative science of the area through adherence to conventional definitions and measures wherever possible.
- Research in this field needs to specify pathways linking changes in self-care behavior to particular outcomes of interest.
- Research in this field must seek to extend the relevance and understandings of self-care impact among diverse populations, particularly among minorities and low-income groups.

The Clinical and Public Policy Implications of Self-Care Practice Among Older Adults

One of our more dramatic observations is the simplicity of some of the most effective self-care interventions. It appears that informational and instructional self-care materials, even when disseminated to target audiences of older adults by mail, have been shown to be effective in improving functional outcomes or lowering costs of health care utilization. Yet, individuals vary considerably in their personal levels of responsiveness to self-care or other health educational messages. Health care providers wishing to incorporate a self-care dimension with their conventional approach to patient care will do well to understand

some of the findings of the growing behavioral literature on individual behavioral response to illness symptoms.

From a public policy viewpoint, there are obvious decision points with respect to self-care intervention policies. The loci of interventions is a major aspect of some disagreement within the field. There is a growing but still developing literature on the individual, lay decision-making context within which self-care strategies are considered as a part of a larger lifecourse approach to health and illness. Emerging are strong voices urging the incorporation of self-care within organizational and societal efforts to restructure health care systems. In this latter respect, self-care is seen as a major dimension by which the forces creating the demand for expensive formal health care may be more effectively managed.

There is a general feeling that some of the new knowledge now needed in this area might be gained by fusing an interest in self-care with already operational large-scale studies of health care utilization behavior, or in secondary analyses of the program outcomes of such projects as those designed to increase the frequency of end-of-life decisions (i.e., "living wills" and "advance directives") involving older adults and their families.

From a policy point of view, one of the most troubling aspects of this whole field is the question of the most appropriate setting or context for self-care education or practice. If it is to be a clinical care setting, then concrete efforts must be made to make health care providers more aware of the role and potential of self-care and to train them in more effective methods for reinforcing the idea of learning these skills among their older adult clients and patients. The general movement toward managed care is now encompassing larger numbers of older persons. While there is much speculation about the impact of managed care arrangements on doctor-patient interactions, still unknown is the full impact of evolving care arrangements on the encouragement of different self-care practices for patients with varying health statuses.

Finally, there is the policy implication of the presumed substitutability of self-care for other forms and types of health care and personal assistance among older adults of differing ages. We need more information about the extent to which lay caregivers or those providing social support tend to maintain their availability when lay persons assume greater levels of self-care.

Conclusion

As our nation moves to deal with the challenge of defining the most appropriate and effective strategies, programs and policies to assure the availability of adequate health and social services for our rapidly increasing older adult population, self-care and programs to increase the readiness of older adults to

practice these skills should gain greater attention. The chapters in this volume clearly indicate the depth and speed with which the literature of this field has grown over the space of two decades. Self-care, while once an ideological threat to some providers of formal health care services, has now been fully integrated with the care offered to patients who suffer from chronic disabling conditions. We have yet to realize the full potential of self-care strategies for general health maintenance and the enhancement of functional independence of older adults in the United States. These chapters have outlined a wide spectrum of new research opportunities and challenges for the decade ahead, ones we hope our readers will accept with enthusiasm and new levels of commitment.